

# American Indian Alaska Native National Advisory Council Susan G. Komen for the Cure®

## Members

- ✦ Linda Burhansstipanov (Chair), MSPH, DrPH, CHES, (Cherokee Nation of Oklahoma), Pine, Colorado
- ✦ Florence Tinka Duran (Rosebud Sioux Tribe), Rapid City, South Dakota
- ✦ DeAnna Fay Finifrock, RN, PHN, MSN, (Fond du Lac), Cloquet, Minnesota
- ✦ Carolee Dodge Francis, Ed.D (Oneida Nation of Wisconsin), Iron Mountain, Michigan
- ✦ Lydia Hubbard-Pourier, MPH (Navajo-Tohono O'odham), Phoenix
- ✦ Phyllis Pettit Nassi, (Otoe Missouria and Cherokee), Salt Lake City
- ✦ Nellie Sandoval, MS, (Navajo Nation), Farmington, New Mexico
- ✦ Delight Satter, MPH, (Umpqua/Kickitat of the Confederated Tribes of Grand Ronde), Los Angeles
- ✦ Carmelita Warnego Skeeter (Citizen Nation Potawatomi Tribe), Tulsa, Oklahoma
- ✦ Arlene Wahwasuck, RN, MSN, (Prairie Band Potawatomi Nation), Horton, Kansas
- ✦ Celeste Whitewolf, JD (Confederated Tribes of Umatilla), Portland, Oregon



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## Who is an "Indian"?

- ✦ "American Indian" This includes enrolled members of Federal and/or State recognized tribes as well as people who identify themselves as "American Indian".

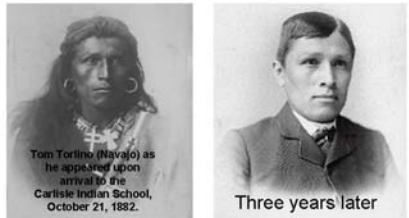
**What are the differences in the American Indians history?**

- ✦ Since the formation of the union, the U.S. has recognized Tribal governments as sovereign nations
- ✦ The federal government has enacted numerous statutes and regulations that establish and define who an Indian is and their relationship to the federal government

**Indians are not just . . .**

- . . . a minority . . . a special interest group
- . . . a political party

**First They Took Our Land  
...Then They Took Our Children**



Tom Torlino (Navajo) as he appeared upon arrival at the Carlisle Indian School, October 21, 1882.

Three years later

Indian Boarding Schools

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## Key Points In Indian History or Federal Indian Policies

- 🕒 1608-1830 Treaty Making (Policy)
- 🕒 1802 - War Department
- 🕒 1824 - Bureau of Indian Affairs (BIA)
- 🕒 1830-1850 Removal Policy
- 🕒 1849 - BIA moved under Department of Interior
- 🕒 1850-1871 Establishment of Reservations Policy
- 🕒 1871-1928 Assimilation and Allotment Era (Policy)
- 🕒 1887-The General Allotment or Dawes Act
- 🕒 1924 - Indian Citizenship Act of 1924 (41 Stat. 408)
- 🕒 1934 - Indian Reorganization Act
- 🕒 1940's – 1980's Indians fought for the right to vote
- 🕒 1953 - Termination Act
- 🕒 1968 – Self-Determination (PL 93 -638)




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## Many Contemporary (within last 40 years) Events Contribute to Barriers and Issues

- 🕒 1968 American Indian Movement and Alcatraz Island – reclaiming disserted federal lands as per federal law
- 🕒 1970's sterilization of American Indian women without informed consent
- 🕒 Many other events (NY / Canada Mohawk siege; Rosebud; Wounded Knee [recent event, not the original event])



### Sovereignty and Gaming



- 🕒 Only a small percentage of tribes have gambling and casino gaming.
- 🕒 Of those who do, many have successfully used resources to build community infrastructure
- 🕒 Most tribes are still:
  - 🕒 Small, rural
  - 🕒 Greatly lacking in having resources or capacity to meet the health and public health needs of their people

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## 2000 U.S. Census: Numbers of AIAN

- ✦ American Indian and Alaska Native (AIAN) population is increasing at about 1.8% a year
- ✦ 2.2 million reported AIAN Race "alone" (4.1 million AIAN alone or in combination with other race(s))

28% increase in "AIAN alone" since 1990 Census

### Demographics: states with >100,000

States with more than 100,000 AIAN residents.

|                      |                |
|----------------------|----------------|
| California (628,000) | North Carolina |
| Oklahoma (392,000)   | Michigan       |
| Arizona              | Alaska         |
| Texas                | Florida        |
| New Mexico           |                |
| New York             |                |
| Washington           |                |

Combined, these states have 62% of the total AIAN population

### 2000 Census Demographics

| Characteristic | AIANs    | US All Races |
|----------------|----------|--------------|
| Median Age     | 28 yrs.  | 35.3 yrs.    |
| Median Income  | \$31,799 | \$42,148     |
| Poverty Rate   | 25.9%    | 11.3%        |
| High School    | 70.9%    | 80.4%        |

Thank you, Steve Benson, MPH, Office of Public Affairs, ATSDR, CDC, for sharing his slides, modified by Linda B.

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## 2000 U.S. Census: Where AIAN Live

Note the areas of elevated number of AIANs = Places unequal burden on areas that have high numbers of AIANs

- ✦ 43% of AIAN lived in the West
- ✦ 9% in the Northeast
- ✦ 31% lived in the South
- ✦ Approximately 64% live in urban areas (live in *all* 50 states)
- ✦ 17% lived in the Midwest

### Indian Lands: 1492 to Present

1492  
Arrival of Columbus

1790  
Indians Forced Inland

1830  
"Indian Country"

1860

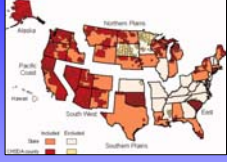

### Urban Indian Health Organizations Nationwide (only a total of 34 urban Indian clinics)

(2% of the total 800 hospitals in the country of which 1% is for mental health / drugs)

Many of these urban Indian clinics are "referral" only (i.e., they do not provide clinical services & all cancer is referred)

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### Cancer Age-Adjusted Incidence and Mortality Data


Differences in the incidence, prevalence, mortality and burden of cancer and related adverse health conditions that exist among specific population groups in the U.S.\*

- ☞ Gender
- ☞ Age
- ☞ Ethnicity
- ☞ Education
- ☞ Income
- ☞ Social class
- ☞ Disability
- ☞ Geographic location
- ☞ Sexual orientation

\*Cancer Health Disparities Progress Review Group, Making Cancer Health Disparities History: Report of the Trans-HHS Cancer Health Disparities Progress Review Group. US DHHS, March 2004, p. vi

|        | US    |       | So. Plains |       | No Plains |       |
|--------|-------|-------|------------|-------|-----------|-------|
|        | AIAN  | NHW   | AIAN       | NHW   | AIAN      | NHW   |
| All    | 368.4 | 475.9 | 492.6      | 461.2 | 538.1     | 464.8 |
| Breast | 85.3  | 134.4 | 115.7      | 129.6 | 115.9     | 130.3 |


Source: Cancer registries in Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR) and National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results Program (SEER) D. Espy, Monograph Group.




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### Patterns of Breast Cancer and AIAN Characteristics

- ☞ More cancers among AIANs who live in Alaska, Northern Plains and Southern Plains
  - ☞ BUT, even in Southwest, selected types of cancer continuing to increase
  - ☞ Burden of disease is extreme
- ☞ Average interval from biopsy (diagnosis) to initiation of cancer care is 6 months for AIAN women and 9 months for AIAN males
- ☞ Average age of AIAN population is younger in comparison to US All Races and our people are diagnosed at younger ages: ½ of AIAN breast patients younger than 50
- ☞ Co-morbidity: 15%-25% of AIAN cancer patients are diabetic
- ☞ Access to cancer resources outside of IHS / Tribal / Urban (ITU) clinical settings insufficient or non-existent
  - ☞ About 1/3 have private health insurance (**NOTE: IHS is NOT health insurance**)
  - ☞ ½ of AIAN cancer patients fight for Medicaid (young at time of dx) or Medicare
  - ☞ 64+% of AIANs live in urban areas of which there are only two I/T/U cities that provides cancer care:
    - ☞ Anchorage
    - ☞ Fairbanks






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**Barriers and Issues that CAN be Addressed in Culturally Respectful Manners**

- ☞ No access to screening services within local community
- ☞ Clinical services not available in the evening
- ☞ Clinical services not available on Saturdays
- ☞ Patient preference for specific gender for health care provider
- ☞ Long waiting times
- ☞ Language issues
- ☞ Lack of living "infrastructure"
  - ☞ Lack of
    - ☞ water
    - ☞ electricity
    - ☞ sanitation
    - ☞ potable water
- ☞ Health insurance coverage
  - ☞ Underinsured
  - ☞ Uninsured
- ☞ Employment
- ☞ Transient population (new contact info every 18 months)
- ☞ Diversity among the tribal Nations
- ☞ Cultural awareness of how health is perceived and how care is accessed
- ☞ Education/outreach
- ☞ Literacy level
- ☞ Acknowledgment gaps & barriers exist
- ☞ Cultural beliefs
- ☞ Diversity within diversity
- ☞ Use of Traditional Indian Medicine



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**AIAN Public Health: Challenges/Obstacles**



- ☞ Few AI/AN public health professionals
- ☞ Limited familiarity with AI/AN policies
- ☞ Complexities/logistics – over 500 tribes
- ☞ Public health legislation/legal foundations
- ☞ Lack of public health infrastructure
- ☞ Funding issues
  - ☞ Lack of AI/AN-specific funds
  - ☞ Data errors under-count AIAN health problems
  - ☞ Limitations/problems of categorical funds
  - ☞ Funds received by CDC/ATSDR often designated for state health departments
  - ☞ Tribal ineligibility for certain funds
  - ☞ Current funding policies/procedures often put states and tribes in competition for same funds

Thank you, Dean Seneca, MPH, ATSDR, CDC, for sharing the slide



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### Federal and State Governments Working with Tribal Nations and Urban Indian Programs

#### Respective Core Values

| Traditional Native         | Main Stream Society, U.S.     |
|----------------------------|-------------------------------|
| Cooperative                | Competitive                   |
| Group/Tribal Emphasis      | Freedom, Progress, Efficiency |
| Extended Family Important  | Individualism                 |
| Modesty                    | Sexy                          |
| Patience/Passive (SW)      | "Getting Ahead in Life"       |
| Generous/Non-Materialistic | Material Comfort              |
| Respect for Age            | Youth                         |
| Spirituality               | External Conformity           |
| Indirect Criticism         | Direct Criticism              |
| Harmony with Nature        | Conquest of Nature            |

Most Tribal Nations have many challenges working with State and Federal Agencies primarily due to misinformation about AIANs Diverse Cultures, Sovereignty, Indian Health Service Misconceptions, and long and repeated history of unethical behavior and practices by the government to the ITUs. ITU Programs funded directly by government *more likely* to succeed.

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### Frontier Challenges

- Remoteness (no telephone or computer access)
- Snowed in / isolated (AK = no roads to most of the state; boats, but rivers freeze; air travel and no guarantee you can land; <50 below planes cannot fly)
- Monsoons wash roads out
- Vehicles too unreliable to drive out



“When I was diagnosed with cancer, I had to go to Seattle for surgery. It was very scary...The travel costs and the long way we have to fly is the hardest part of having cancer.”

Frances Lampe passed away July 2004  
 Photo by Clark James Mishler

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**Department of Health and Human Services, President's Cancer Panel  
 2002 Annual Report, Facing Cancer in Indian Country: The Yakama Nation and Pacific Northwest Tribes: US DHHS, NIH, NCI: December 2003.**

**Excerpt from the Yakama Report**

“It took me six months to get a referral out because I am not a Quinault but I lived in their service area, [and] my Quileute tribal service area could not give me the referral because I was out of jurisdiction of their service unit. Things like that need to be looked into and addressed because a lot of times we cannot marry someone from our own reservation because we are all related in one way or another so you have to go look outside of your reservation to go marry someone you are not related to.”

*Ann Penn-Charles, Breast Cancer Survivor, Community Health Representative, Hoh Indian Tribe, Washington*

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**Challenges, Barriers, Issues**

**Selected Behavioral Measures Related To Breast Cancer**

- Age at the time of exposure to environmental contaminant may determine increased risk
- Obesity ranges from 38-75% among tribal Nations
- Habitual tobacco use ranges from 17% to 71% among tribal Nations
- Regular physical activity (3 times a week for 30 minutes or more) ranges from 15% to 30% among tribal Nations

Physical activity data source not confirmed

**Frontier / Rural Regions and Internet Access**

Initial surveys with community members:


If this information was available on the Internet, would you be able to use it?

| 2002 | 2006 |
|------|------|
| 15%  | 35%  |
| 30%  | 40%  |
| 30%  | 15%  |
| 25%  | 10%  |

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**Issues Common with Other Groups**


**Excerpts from Native Breast Cancer Survivors:  
Disparity = medical language is unfamiliar**



But the thing that I wasn't ready for was the 17 lymph nodes that they had to remove along with my breast. And I said, what does a lymph node do anyway? What do I need it for?

Cyndi Thornton  
Cherokee  
Diagnosed:  
1990 breast cancer

**Excerpts from Native Breast Cancer Survivors: Disparity: no time to think; everything is rush rush rush**



Then I went back five days later and they removed the fifteen lymph nodes and glands, and that was the way it happened, and it all happened so fast, it was kind of a surprise.

Mary Lou Davis  
Caddo / Cherokee  
Diagnosed:  
1993 breast cancer

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**Common AIAN Myths and Facts**

- 🗑️ **MYTH: AIAN don't pay taxes**  
🗑️ **FACT:** AIANs pay US taxes; taxes taken out of check as with other US Citizens.
- 🗑️ **MYTH: AIAN get free education**  
🗑️ **FACT:** AIAN are *supposed* to have special education funding; however, it is extremely under-funded and limited to few AIANs; AIANS must also pay back the loans.
- 🗑️ **MYTH: AIAN don't serve in the armed forces**  
🗑️ **FACT:** AIANs are over-represented in the Armed Forces in proportion to the US population base and other racial groups.
- 🗑️ **MYTH: Most AIAN receive a monthly check from the government**  
🗑️ **FACT:** The majority of these checks have yet to be released by the BIA and is currently under a case action lawsuit. Few AIANs receive any payment even though these are specified within federal treaties.
- 🗑️ **MYTH: All AIAN tribal Nations have gambling casinos**  
🗑️ **FACT:** Less than 1/3 of all federally recognized tribal Nations have gambling casinos.
- 🗑️ **MYTH: AIAN are considered "minorities" similar to other racially under-served populations**  
🗑️ **FACT:** AIANs are the only group in the US who are required to carry a card to prove who we are.

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### Strengths of AIAN Cultures

**Strengths: Resilience**

- Ups and downs of life, more programs offered in AIAN settings to emphasize resilience and respect for traditional values



**AIAN Contribute to Society**

- AIAN pay taxes, hold jobs that help society (e.g., teachers, Hot Shot Fire Fighters), and share healing and traditional knowledge with those who need it.



**Ancestors / Elders**

- Respect for ancestors, elders and traditional practices





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### Strengths of AIAN Cultures



**AIAN Traditional Beliefs**

- Traditional Indian Medicine, spirituality, and healing
- Uses include herbal teas for pain relief for unmanaged cancer pain, etc.



**Family**

- Family (as with most, if not all cultures) remains one of the core strengths within the diverse AIAN cultures




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### Strengths of AIAN Cultures


**US Armed Forces**

- Respect our Veterans
- AIAN are over-represented in the armed forces
- AIAN hold unique roles in armed forces: Apache Tunnels in Vietnam; Code Talkers in WWII




**Community**


- "Community" includes protecting the family, clans, extended family, neighbors
- Note: "Clans", "Bands"
- Being AIAN is more than simply checking a box on a survey; it implies a responsibility to give back to



**Home Care**

- Palliative care
- End-of-life ... most Natives die in their homes





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### Strengths of AIAN Cultures


**Protect the Environment**

- Respect for ties with the environment and the land ("the balance")



- We are Survivors!





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